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# **Exploration of How Women Make Treatment Decisions** After a Breast Cancer Diagnosis

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reast cancer is the most frequently diagnosed form of cancer in women in the United States (American Cancer Society [ACS], 2011). An estimated one in eight American women will develop breast cancer at some point in their lives. More than 229,000 cases of breast cancer were estimated to be diagnosed in women in the United States in 2012 (ACS, 2012).

Many studies that examine physical and psychosocial adaptation after the diagnosis of breast cancer have been conducted with women (Bettencourt, Schlegel, Talley, & Molix, 2007), and much research has been done to assess coping styles and quality-of-life issues in breast cancer survivors (Webb & Koch, 1997). However, understanding is inadequate in how women make decisions about treatment options after being diagnosed with breast cancer (O'Brien et al., 2008).

Based on the prevalence of the disease, nurses should be knowledgeable about risk factors, incidence, and medical and surgical treatment options, as well as the physical and psychosocial needs of patients with breast cancer. Nurses often educate patients on health care, disease prevention, and health promotion; they must be able to provide comprehensive care to women diagnosed with breast cancer and assist them in making informed and satisfied decisions.

The purpose of this study, which used a mixedmethods approach, was to explore how women made treatment decisions after receiving a diagnosis of breast cancer. The specific aims of the study were to (a) assess the information needs women have after receiving a diagnosis of breast cancer, (b) investigate how decisions about treatment options are made, and (c) assess personal responses to the decisions made.

# Background

Receiving a diagnosis of breast cancer and learning about the number of treatment options available can

**Purpose/Objectives:** To examine the information needs of women after receiving a diagnosis of breast cancer, investigate how decisions about treatment options are made, and assess personal responses to the decisions made.

**Design:** Mixed-methods approach using quantitative and qualitative data.

**Setting:** The University of Kansas Medical Center and Quinn Plastic Surgery Center, both in the midwestern United States.

**Sample:** 102 breast cancer survivors who had completed all forms of treatment for at least three months and less than five years.

**Methods:** Phase I participants completed five questionnaires about informational needs, confidence and satisfaction with the decision, decisional regret, and conflict. In phase II, 15 participants were purposively sampled from the 102 survivors to participate in a focus group session. Data analysis included frequencies and multiple regression for phase I and qualitative content analysis for phase II.

**Main Research Variables:** Informational needs, confidence and satisfaction with the decision, and decisional regret and conflict.

**Findings:** The variables (widowed, confidence and satisfaction with decision, and decisional conflict and regret) significantly (p = 0.01) accounted for 14% of the variance in informational needs. Two themes emerged from the study: (a) feelings, thoughts, and essential factors that impact treatment considerations, and (b) tips for enhancing treatment consideration options.

**Conclusions:** The study's results show that women viewed informational needs as very important in making treatment decisions after being diagnosed with breast cancer.

**Implications for Nursing:** The treatment team should provide the information, with consideration of the patient's personal preferences, that will assist women to make informed, confident, and satisfied decisions about treatment choices.

be an extremely threatening and frightening event for most women (Galloway et al., 1997). The disease threatens physical and psychosocial well-being in women (O'Brien et al., 2008). A patient's personal view strongly influences their healthcare decision-making processes. Nazareth et al. (2008) found that the important themes in decision making include the patients' actions, role of significant others, treatment decision choices, and communication with and between healthcare providers.

After being diagnosed with breast cancer, women commonly are exposed to numerous doctors in a short time span to discuss the disease process, prognosis, and treatment options. All of that information and the need to assimilate new knowledge can be overwhelming to the patient. As a woman attempts to deal with threats to physical and psychosocial well-being, information processing is on overload (Spittler, 2008). In addition to having to make decisions, the diagnosis of breast cancer can evoke concerns about death and dying, and the patient is faced with possible alterations in relationships with others, financial concerns, and body image issues.

Hallenbeck (2002) noted that decision making is dependent on much more than weighing facts, risks, and benefits. Using a qualitative approach, Hallenbeck (2002) described *explanatory narratives* to examine how women make medical decisions about hormone replacement therapy. He found that patients primarily rely on past experiences, relationships with their physician and healthcare team, personal fears, and belief systems when making medical decisions. In addition, Graydon et al. (1997) studied informational needs of patients with breast cancer and identified the highest area of needs revolved around the disease process, diagnostic tests, and treatments.

In the authors' experience, stress and anxiety resulting from the diagnosis of breast cancer, as well as patients' perceived urgency of the circumstances, can lead some women to make decisions they later regret. Prior research demonstrated that a potential exists for the development of decision regret as patients participate in making healthcare decisions (Brehaut et al., 2003). Healthcare decisions that have a poor outcome often can lead to regret, and regret can be a highly negative emotion. Brehaut et al. (2003) posited that little is known about the role that post-decision-making regret plays in subsequent behavior; this field of study is still in an infancy stage. Janis and Mann (1977) stated decisional conflict will inevitably result when a person has not had time to process information or a lack of available or preferred alternatives exists. Decisional conflict is defined as a state of uncertainty that occurs when decisions involve unknown outcomes, are associated with a high degree of risks, when the ratio of benefits to loss is unclear and needs to be critically examined and assessed, or regret when it is a likely consequence of making decisions that involve tradeoffs.

Being confident in and satisfied with the decision is a desired outcome for most women. Estes and Hosseini (1988) reported that extremely low confidence levels related to decision making can be paralyzing and debilitating. On the other hand, very high confidence levels may result in reckless behavior, excessive risk, or preventable loss. Past research on measures of patient satisfaction primarily has addressed satisfaction with the healthcare team, medical care, and outcomes, but little is known about satisfaction with a healthcare decision (Holmes-Rovner et al., 1996). Collaborative efforts between patients and healthcare providers are expected and encouraged in the current healthcare arena. Often, the patient and provider are involved in situations where no clear or perfect solution exists to a problem, and more research is needed to account for the dynamics involved in making healthcare decisions.

# **Theoretical Framework**

The theory of decisional conflict developed by Janis and Mann (1977) was used as a framework to guide the current study. Antecedents include communication, negative consequences from previous decisions, and other predisposing characteristics of the individual (e.g., personality). Mediating factors include the risks if no course of action taken, the impact of the risks, hope for a more favorable solution, and adequate time to research and contemplate different options. Consequences include unconflicted adherence, unconflicted change, defensive avoidance, hypervigilance, and vigilance (the preferred outcome for informed and satisfied decisions). Signs of decisional conflict might encompass verbalization about choices, fear of the unknown or unwanted results, vacillation between treatment options, and delayed decision making that may cause moderate to severe stress.

The goals of this study were to examine informational needs women have after receiving a diagnosis of breast cancer, investigate how decisions were made about treatment options, assess the personal responses to the decisions that had been made, and provide members of the treatment team with information to help patients with breast cancer make treatment decisions with which they are satisfied. The constructs of informational needs, confidence, decisional conflict, satisfaction, and regret were measured. Women need to understand their options, available resources, what the decision means to them personally, and the effectiveness of each treatment to make an informed and satisfied treatment decision after being diagnosed with breast cancer.

# **Methods**

This study used a mixed-methods design to collect, analyze, and merge quantitative data collected in phase I with qualitative data collected via focus groups in phase II. The description of qualitative explanatory narratives (Hallenbeck, 2002) was used as a method for phase II of the study to assess how women made decisions about treatment options.

## Setting and Sample

Participants (N = 111) were recruited from the University of Kansas Medical Center's breast cancer survivorship clinic and a private plastic surgery practice, Quinn Plastic Surgery Center, both in the midwestern United States. Criteria for study inclusion were women older than 18 years who were breast cancer survivors. Participants had to be able to read, write, and speak English; be able to give informed consent; have access to a computer; and be able to perform simple computer functions to complete five questionnaires. Participants had to be finished with all forms of treatment (e.g., surgery, chemotherapy, radiation, any type of cytotoxic therapy, reconstructive procedures) for at least three months and less than five years, except for long-term antihormonal therapy. Nine participants were excluded, resulting in a final sample size of 102; two participants still were being treated for cancer and seven were excluded because of missing data.

Phase II data were collected during two separate focus group sessions. Based on the quantitative survey scores, samples were selected that indicated high regret and conflict scores and low satisfaction with their decision (n = 8) and low regret and conflict scores and high satisfaction with their decision (n = 8). One participant did not take part in the focus groups because of a scheduling conflict, resulting in a final sample of 15.

#### Instruments

Participants from phase I completed five surveys: (a) **Toronto Informational Needs Questionnaire–Breast Cancer (TINQ-BC)**, (b) **Decisional Conflict Scale**, (c) **Decision Regret scale**, (d) **Confidence in Decision scale**, and (e) **Satisfaction With Decision scale**. Table 1 provides the operational definitions and citations for the psychometric properties of the measures. In addition, demographic characteristics (e.g., race, marital status, education) were collected.

| Instrument  | Items and Definition   | Reported Psychometric Properties   |
|---|--|--|
| Confidence in Decision<br>scale (Estes & Hosseini,<br>1988; Holmes-Rovner et<br>al., 1996; Youngblut &<br>Casper, 1993) | One-item scale ranging from 1–10; higher score<br>represents higher confidence level.<br>The level of confidence in the treatment deci-<br>sions made  | No information available on the psychometric properties<br>of this scale<br>Psychometric properties of single-item indicators have<br>been reported in the literature to be valid and reliable<br>measures.  |
| Decisional Conflict<br>Scale (O'Connor, 1993)   | <ul> <li>16 items; score range = 0–100</li> <li>Five-point Likert-type scale ranging from strongly agree to strongly disagree; higher scores represent higher degrees of decisional conflict.</li> <li>A state of uncertainty, lack of information, unclear values, or lack of support that may contribute to ineffective or dissatisfied decision making</li> </ul> | Cronbach $\alpha = 0.93$<br>Construct validity was conducted and the subscales and<br>total score were correlated to constructs of knowledge,<br>regret, and discontinuance.<br>Known group differences also were used to establish<br>construct validity. |
| Decision Regret scale<br>(Brehaut et al., 2003)   | 5 items; score range = 0–100<br>Five-point Likert-type scale ranging from strongly<br>agree to strongly disagree; higher scores rep-<br>resent higher decision regret.<br>The degree of distress or remorse, if any, about the<br>treatment decision that had been made  | Cronbach $\alpha = 0.88$<br>Total scale is correlated with the Satisfaction With Deci-<br>sion scale, Decisional Conflict Scale, and with ratings of<br>overall quality of life.   |
| Satisfaction With Deci-<br>sion scale (Holmes-<br>Rovner et al., 1996)  | 6 items; score range = 6–30<br>Five-point Likert-type scale ranging from strongly<br>disagree to strongly agree; higher scores rep-<br>resent greater satisfaction with the decision.<br>The degree of satisfaction with the healthcare<br>decisions that had been made  | Cronbach $\alpha = 0.98$<br>Scale was found to discriminate between patients who<br>were sure what to do as opposed to those who were<br>less sure about what to do.   |
| Toronto Informational<br>Needs Questionnaire–<br>Breast Cancer (Gallo-<br>way et al., 1977)                             | <ul> <li>51 items; score range = 51–255</li> <li>Five-point Likert-type scale ranging from not important to extremely important; higher scores represent greater informational needs.</li> <li>Importance of knowledge related to disease process, investigative tests, treatments, physical, and psychosocial needs</li> </ul>                                      | Cronbach α = 0.97<br>Content validity established with 11 oncology nurses and<br>34 women without a breast cancer diagnosis.<br>Construct validity reported on compatibility with the<br>theoretical model and the scale.                                  |

Table 1. Measures and Operational Definitions for the Scales Completed by the Study Participants

## **Data Collection**

Participants were asked to complete an information form to obtain demographic data, and the researcher determined whether they met the inclusion criteria. Once inclusion criteria were met, an instruction sheet was provided for directions on completing the surveys. The participants were requested to complete the five online survey tools. Instructions for completion of the surveys were provided once the Web site was accessed. The data were secured on a password-protected server and were backed up daily. The researcher worked with a designated survey designer at the academic medical center who entered the survey online and transmitted the data. Only the researcher and the survey designer, who signed confidentiality agreements, had access to the confidential electronic data.

Two separate focus group meetings were conducted. Focus group participants were selected purposively from the participants who took part in phase I of the study. A total of 21 participants met the criteria for participation in the focus groups, of which 16 initially agreed but one canceled because of a schedule conflict. Participants for phase II of the study were selected based on scores from the Satisfaction With Decision scale, Decisional Conflict Scale, and the Decision Regret scale. Scale scores from the upper one-third and the lower one-third of the instruments measuring dissatisfaction with decision, degree of decisional conflict, and decision regret were analyzed. The low-regret individuals were those participants who scored higher than 4.8 on the Satisfaction With Decision scale, less than 10 on the Decisional Conflict Scale, and less than 6 on the Decision Regret scale. The high-regret individuals were those participants who scored less than 4 on the Satisfaction with Decision Scale, higher than 26 on the Decisional Conflict Scale, and higher than 9 on the Decision Regret Scale. A semistructured interview was used to guide the discussion.

Approval for the study was obtained from a Cancer Center Protocol Review and Monitoring Committee and the institutional review board at the University of Kansas Medical Center in Kansas City. Identifying data were removed to protect the confidentiality of participant responses.

#### **Data Analysis**

Descriptive statistics using SPSS<sup>®</sup>, version 16.0, were used to describe the data and determine the sample for the focus groups. Multiple regression statistical tests were used to analyze the relationship of the demographic characteristics, confidence, satisfaction, regret about decisions, and degree of decisional conflict with informational needs in making decisions about treatment options. A priori power analysis determined a sample size of 97 participants was needed to perform multiple regression analysis procedures with the level of significance set at 0.05, power at 0.8, a medium effect size, and six predictor variables.

Analysis of variance with follow-up t-test statistics was conducted with all of the demographic variables race, marital status, education, employment, menopausal status at the time of diagnosis, living location, time since breast cancer diagnosis, first-degree relative with breast cancer, and tumor stage at time of diagnosis, as well as the dependent variable, informational needs. With the exception of marital status, no significant differences existed (p > 0.05) on informational needs among any of the demographic characteristics, eliminating these variables from additional analysis. For current marital status, the widowed group ( $\overline{X}$  = 170) was significantly different ( $F_{[3,95]} = 3.28$ , p = 0.02) from the other groups (single  $\overline{X} = 207$ , married  $\overline{X} = 211$ , and divorced  $\overline{X}$  = 208). A dichotomous variable was created that was defined as widowed now (1) and all other marital status categories (0); these were used in the multiple regression procedures.

Qualitative content analysis was used to analyze phase II data. The six steps outlined by Elo and Kyngäs (2008) were used for the content data analysis. The procedures started with data preparation (sessions were tape-recorded, transcribed verbatim, and checked for accuracy), followed by an iterative process that was used to extract, condense, and organize codes from the data. Finally, a coding sheet was developed and used to group codes, form categories, and develop the themes. Peer debriefing throughout the data analysis and interpretation of the findings with two researchers was used to establish credibility.

## Results

The 102 participants primarily were Caucasian, married at the time of breast cancer diagnosis, and still married at the time of survey completion (see Table 2). Descriptive results for the measures are reported in Table 3. Women diagnosed with breast cancer reported that their information needs about breast cancer, disease process, prognosis, and treatment options were "very important" in making informed decisions. Participants rated their satisfaction and confidence levels as high. In addition, 31% of the women were "totally satisfied" with the healthcare decisions they had made, and only 8% were "totally dissatisfied" with their decisions. The degree of decisional conflict reported by women in this study was low; only 1% of the study sample reported high decision conflict, and 16% reported no decisional conflict. The degree of decision regret also was very low. The majority of women (79%) reported low decision regret and, of those, 44% had no decision regret.

The relationship of the demographic characteristic "widowed now," confidence in decisions, satisfaction with the decision, degree of decisional conflict, and regret about the decision, with informational needs of the study participants in making decisions about treatment options, were examined. Pearson correlations among the independent variables ranged from -0.59 to 0.5. Regression analysis procedures were completed controlling for "widowed now," and the other four independent variables were entered in a block. The linear weighted combination of the five variables significantly (p = 0.01) accounted for about 14% of the variance in the informational needs of the participants (see Table 4).

Although a small sample, women who were widowed had lower informational needs ( $\overline{X} = 171$ , SD = 60.3, n = 7) compared to the other participants ( $\overline{X} = 210$ , SD = 29.3, n = 95). Widowed women also reported lower decisional conflict ( $\overline{X} = 12.2$ , SD = 17.6) and lower levels of support ( $\overline{X} = 1.1$ , SD = 2.3) when compared to others ( $\overline{X} = 20.6$ , SD = 16;  $\overline{X} = 2.2$ , SD = 2.4, respectively).

In phase II, the focus group participants (n = 15) were not significantly different on the demographic characteristics from the total sample except for employment status. Participants who worked full-time (60%) or were retired (20%) were the same, but 20% were unemployed (compared to 10% of the full sample) and none worked part-time (compared to 25% of the full sample).

Two themes emerged from the subcategories and categories through the content analysis. The first theme involved feelings, thoughts, and essential factors that impact treatment considerations, and the second theme included tips for enhancing treatment consideration options. The first theme included three categories: personal thoughts and feelings, decision aids, and deterrents. The initial personal thoughts that women generally gave as responses after being diagnosed with breast cancer were feelings of shock and disbelief. Some women were convinced they were going to die after receiving the diagnosis of breast cancer. Women expressed that they wanted a doctor that listened, had a good bedside manner, and understood personal preferences. As one woman reported, "Sometimes the first initial contact, it can really screw up the whole process or be a good starting point."

Women voiced the desire to get the cancer out as quick as possible. Women said things such as, "Like most of us, we wanted it out yesterday, you know, when they find it," and "I did not want to wait any longer." A few of the women talked about the sadness of losing one or both breasts, but again, survival outweighed these self-image issues. As one participant explained, "[My breasts] were my favorite part of my body and it was a very difficult decision to make but, like other things or activities I have had or done, I [was] not going to let what I liked best kill me."

#### **Table 2. Participant Characteristics**

| Table 2. Participant Chara                           | cteristics                |                         |
|--|---------------------------|-------------------------|
|  | Total Sample<br>(N = 102) | Focus Group<br>(N = 15) |
| Characteristic                                       | n                         | n                       |
| Race   |                           |                         |
| Caucasian  | 99                        | 15                      |
| African American                                     | 3                         | _                       |
| Marital status at diagnosis                          |                           |                         |
| Single   | 5                         | 1                       |
| Married  | 82                        | 11                      |
| Widowed  | 4                         | 1                       |
| Divorced   | 10                        | 2                       |
| No response  | 1                         | _                       |
| Current marital status                               | 6                         |                         |
| Single<br>Married                                    | 74                        | - 11                    |
| Widowed  | 7                         | 2                       |
| Divorced   | 12                        | 2                       |
| No response  | 3                         | _                       |
| Education  |                           |                         |
| High school  | 15                        | 3                       |
| Associate's degree                                   | 10                        | 1                       |
| Some college   | 25                        | 4                       |
| Bachelor's degree                                    | 28                        | 4                       |
| Some graduate  | 9                         | -                       |
| Master's degree                                      | 12                        | 3                       |
| Higher than master's degree <b>Employment status</b> | 3                         | -                       |
| Unemployed   | 10                        | 3                       |
| Part-time  | 25                        | _                       |
| Full-time  | 54                        | 9                       |
| Retired  | 11                        | 3                       |
| No response  | 2                         | _                       |
| Living location                                      |                           |                         |
| Urban  | 12                        | 13                      |
| Suburban   | 78                        | 1                       |
| Rural  | 10                        | 1                       |
| No response  | 2                         | —                       |
| Menopausal status at diagnosis                       | 65                        | 12                      |
| Premenopausal<br>Postmenopausal                      | 36                        | 3                       |
| No response  | 1                         | _                       |
| Current menopausal status                            | ,                         |                         |
| Premenopausal  | 15                        | 2                       |
| Postmenopausal                                       | 86                        | 13                      |
| No response  | 1                         | _                       |
| First-degree relative with cancer                    |                           |                         |
| No   | 70                        | 8                       |
| Yes  | 30                        | 6                       |
| Unsure<br>No response                                | -<br>1                    | 1                       |
| No response<br><b>Tumor stage at diagnosis</b>       | I                         | —                       |
| 0–l  | 48                        | 9                       |
| II .   | 26                        | 3                       |
| 111  | 14                        | 3                       |
| IV   | 1                         | _                       |
| Unknown  | 13                        | -                       |
| Time since diagnosis                                 |                           |                         |
| 6–12 months  | 4                         | -                       |
| 1–2 years  | 35                        | -                       |
| 3–5 years  | 40                        | —                       |
| More than 5 years<br>Widowed now                     | 23                        | -                       |
| No   | 92                        | 13                      |
| Yes  | 7                         | 2                       |
| No response  | 3                         | _                       |
| ·  |                           |                         |

| Table 3. Descriptive Statistics for the Study Scales |       |      |                |      |  |
|--|-------|------|----------------|------|--|
| Scale  | X SD  |      | Possible Range | α    |  |
| Total TINQ-BC  | 207.7 | 33.4 | 52-260         | 0.97 |  |
| CDS  | 9     | 1.3  | 1–10           | -    |  |
| Total SWD  | 4.2   | 1.1  | 1–5            | 0.98 |  |
| Total DCS  | 20.1  | 16.1 | 0-75           | 0.93 |  |
| Total DRS  | 7.8   | 3.7  | 5–25           | 0.88 |  |
|  |       |      |                |      |  |

N=102

CDS—Confidence in Decision scale; DCS—Decisional Conflict Scale; DRS—Decision Regret scale; SWD—Satisfaction With Decision scale; TINQ-BC—Toronto Information Needs Questionnaire– Breast Cancer

In the feelings category, the main concern cited by the breast cancer survivors regarded survival. The threat of dying was the driving force behind why some women chose certain treatment options. Women felt it was important to, as one participant put it, "find the right doctor, make a game plan, be prepared for consultations by doing preliminary research, take notes during consultations, and build and create their own treatment team." That was confirmed in the full sample, as they reported moderately high concerns about dying ( $\overline{X} = 3.7$ ; range = 1–5) from the TINQ-BC.

Women identified decision aids beneficial in considering treatment options. Those who had personal experiences with breast health concerns and those who had family members who previously were diagnosed with cancer reported that this was beneficial in considering treatment options. One participant said, "My mother had the same type of cancer as I did, but chose not to have both breasts removed. She regretted that decision soon after her mastectomy and worries she will have issues with the remaining breast."

The deterrents category of treatment considerations encompassed aspects of care that were viewed as negative or a drawback to treatment considerations. First, women who had been diagnosed at a higher stage of breast cancer were somewhat limited as to what choices were available. A few women named sexuality concerns and loss of a breast(s) as being hard to take, and this impacted their decision making. Finding out about potential available resources and available support groups "after the fact" also was cited as a deterrent, as one participant explained, "So [support groups weren't] nearly as easy as I had imagined . . . they weren't there when I need them. They really weren't."

The second theme, tips for enhancing treatment consideration options, discussed recommendations for patients with breast cancer and healthcare providers. Recommendations by the study group participants for future patients with breast cancer included being proactive, taking charge, educating yourself, having the doctor recommend reputable books and Web sites, and taking time to absorb the information. Finally, many of the women offered the advice, "Go with your gut feeling" and "Don't let anyone change your mind."

Recommendations to healthcare providers voiced by the participants included (a) telling women the diagnosis is not a death sentence; (b) giving women time to make decisions, as well as giving them permission to postpone or delay some treatment decisions; (c) providing simple guidebooks and comprehensive resource books; and (d) telling women about the potential for future surgeries or the development of lymphedema. As one participant said,

I think what needs to be stressed is . . . that they do have time to take a breath . . . they need to know they have time to absorb it, to just kind of go through a little bit of a fog, cry a little bit . . . and then they need to be given simple things to education [sic] them.

Although the concept of hope was not measured in the study, the focus group participants cited it as important in providing reassurance to women newly diagnosed with breast cancer. Women felt that talking with breast cancer survivors was extremely helpful in providing hope. One participant said, "She was living proof that it's not a death sentence." Healthcare providers also should emphasize the long-term survival rates in certain types of breast cancers.

# Discussion

Based on current literature and evidence, the investigator made several assumptions at the beginning of the study. The first assumption was that the women in the study largely would have felt rushed about making treatment decisions and would not have been given enough time to make an informed decision. However, the findings revealed that the study participants did not feel rushed in making treatment decisions and, for the most part, participants felt they had adequate information to make informed decisions. Second, the investigator assumed that informational needs would be high after receiving a breast cancer diagnosis, and the study participants supported this

| Table 4. Regression Coefficients for the Five |  |
|---|--|
| Independent Variables With the TINQ-BC        |  |

| Scale  | r                                      | b                                      | β                                       | t                                      | р                                    |
|--|--|--|---|--|--------------------------------------|
| Widowed<br>Confidence<br>Total SWD<br>Total DCS<br>Total DRS | -0.3<br>-0.03<br>-0.21<br>0.15<br>0.12 | -33.7<br>2.22<br>-5.02<br>0.23<br>0.65 | -0.266<br>0.09<br>-0.17<br>0.11<br>0.07 | -2.61<br>0.71<br>-1.71<br>0.64<br>0.64 | 0.01<br>0.48<br>0.09<br>0.38<br>0.52 |
|  |  |  |   |  |                                      |

DCS—Decisional Conflict Scale; DRS—Decision Regret scale; SWD—Satisfaction With Decision scale; TINQ-BC—Toronto Information Needs Questionnaire–Breast Cancer assumption in reporting that their informational needs were very important in the decision-making process. Third, the researcher did not anticipate that satisfaction and confidence levels would be as high as what was reported, nor that the degree of decisional conflict and regret would be as low as what was reported. These assumptions were bracketed at the initiation of the study and reviewed by a peer debriefer throughout the study so as to not influence findings.

Body image, sexuality, reproductive issues, and selfesteem were presumed to be key factors in considering treatment options. Although participants reported that body image, sexuality, or reproduction that were altered from surgery or treatment procedures were not major reasons for choosing certain treatment options, body image concerns and reproductive issues did play a role in their treatment choices (e.g., some only chose unilateral mastectomy or lumpectomy with radiation). Findings from the current study differed from Banning's (2007) findings that reported body image, self-esteem, sexuality, and reproduction to be major concerns of women diagnosed with breast cancer from initial diagnosis through treatment and afterward. Although the women from this study cited loss of breast(s) as significant, it was not reported to have caused serious psychological or emotional distress.

The most compelling reason focus group participants chose certain types of treatment was based on their fear of dying or their fear of a cancer recurrence and, for the most part, all other factors took second place. That need for self-preservation and to act now also was reported by Reaby (1998) and Fitch, Gray, Godel, and Labrecque (2008). The following statement was echoed by several of the participants, "My very first reaction to the news that I had breast cancer was that I did not have long to live." The overriding concern of the participants about the fear of death and dying after being diagnosed with breast cancer was validated from findings from the total sample.

Women in the focus groups expressed a need for hope and often chose treatments that most likely would enhance their life expectancy. That underscores the importance of the need for the treatment team to communicate to women that the diagnosis, in most cases, is not a death sentence and that optimism for long-term survival needs to be emphasized. Women still need to be given accurate mortality and morbidity statistics, depending on the stage and grade of their breast cancer, as a prediction for long-term survival rates. However, the women looked to the treatment team for hope and good communication styles, and preferred a shared decisionmaking process. The bottom line was that the women felt it was imperative to take charge and go with their gut feelings when making treatment decisions.

Although a small sample, unexpected results were found with the women who were widowed. That group

of women reported lower informational needs, lower confidence, and lower educational levels. Widowed women reported being more satisfied with the decisions they had made and had less decisional conflict. However, they also cited having lower levels of support, which is expected, as this group had lost their spouses. Additional research needs to be conducted to determine whether these findings would recur and to explore the meaning of this, as it was not explored with the current study participants.

The theory of decisional conflict provided an appropriate framework for examining how women made treatment decisions after being diagnosed with breast cancer. Receiving a diagnosis of breast cancer invokes feelings of stress and can bring about a state of uncertainty in decision making. In addition, according to Janis and Mann (1977), making a decision that involves high risks and unknown outcomes or side effects can be associated with the possibility of experiencing guilt, remorse, or feelings of regret. The study participants voiced these concerns, particularly when they described their initial reactions and impressions to the treatment team. One finding from this study regarded the concept of hope, which evolved as an important part of the treatment process and should be considered as another concept in the model.

The descriptions of antecedent conditions, mediating processes, and consequences by Janis and Mann (1977) were applicable to the women in the current study. Many women referenced how they had a lot going on in their own lives at the time of their breast cancer diagnosis. The diagnosis further complicated their normal routine in dealing with usual activities associated with active and somewhat stressful life situations. Janis and Mann (1977) listed communication as an extremely important antecedent condition to effective decision making. The women in the current study reported good communication with and between healthcare providers as vital. The personality types, personal preferences, and life experiences also were crucial in impacting how they made treatment decisions. The women in this study appeared to go through mediating processes outlined by Janis and Mann (1977) while assessing treatment options and basing some decisions on knowledge, risks, options, and hope for a favorable outcome, as well as having ample time to consider choices. Many participants had experience with the mediating processes by accruing knowledge through personal long-standing breast health concerns or family and friends' experiences with a cancer diagnosis. Generally, the women were motivated to take action and had the cognitive ability to acquire information and knowledge to make an effective decision. Although vigilance, per se, was not measured in this study, these are desired actions that could be interpreted as vigilance. Many described how important it was to gather information on their own to aid in making an individualized treatment decision. The Theory of Decisional Conflict model was supported by the data obtained from this study.

## **Strengths and Limitations**

The focus group participants gave credence to the study and helped to convey a clear picture about the considerations of treatment choices. In addition, the mixedmethods approach helped to merge data and offered insights into how treatment decisions were made. A possible study limitation was the eligibility requirements. Women who were receiving some form of treatment or therapies, or needing additional surgical procedures, were excluded from the study. Those potential participants might have reported lower confidence and satisfaction levels and higher decisional conflict or regret issues because of treatment complications. Another limitation of the study was the potential for participant and researcher bias. The participants in this study may have viewed their decisions more confidently, with higher satisfaction and lower levels of conflict and regret, because they are still alive and have not had a cancer recurrence. Knowing their outcome and having it be positive could contribute to satisfied feelings with the decisions that had been made. An additional question that was not asked in this study was whether the participants had always received care at the same clinical setting. Switching providers or treatment settings may have implied some degree of dissatisfaction, and this factor was not measured in the current study. Bracketing and peer debriefing were used throughout the study to attempt to reduce researcher bias.

# **Implications for Clinical Practice**

Helping patients find and understand their healthcare team may be one of the first things to discuss with women recently diagnosed with breast cancer. *Cancer Guide* (Patient Resource Cancer Center, 2009) outlines a helpful list of the cancer specialists involved in the care of patients with breast cancer. The role each specialist plays may be beneficial in helping patients understand the multidimensional aspects involved in treating breast cancer. Helpful suggestions directed to the healthcare team by the breast cancer survivors were to avoid a disconnect when communicating information and options; to actively listen; to understand the woman's feelings, desires, and needs; and to develop a good working relationship with patients and other healthcare providers. In addition, the women voiced the importance of referral to cancer specialty centers and having up-to-date resources for obtaining information about treatment options. Finally, the participants wanted to be given permission to take time to assimilate information and consider options prior to making treatment decisions.

Nurses caring for patients with a diagnosis of breast cancer, particularly oncology nurses, must educate themselves about the informational needs, fear of dying, fear of cancer recurrence, and need for hope among women diagnosed with breast cancer. Nurses need to provide women with the necessary time and resources to assist them in making informed and satisfied decisions. The need for referral to specialty centers and assigning a nurse navigator to meet the patient's needs should be emphasized.

## **Recommendations for Future Research**

This study should be replicated in a variety of settings and include a greater diversity of educational levels and geographic locations. Altering the eligibility requirements may help to reveal additional findings about how women make treatment decisions. Examining the concept of hope and the concerns about cancer recurrence and dying after receiving a breast cancer diagnosis would be important. Finally, widowed women and their needs related to decision making warrant additional evaluation in future studies.

## Conclusions

This study reported retrospectively how women with breast cancer chose treatment options. It highlighted the need to instill hope and address concerns of cancer recurrence and fears of death and dying. In addition, this study has provided healthcare providers with suggestions about the information needed to assist women in making informed, confident, and satisfied decisions about treatment choices.

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